

Many related concerns are reflected in the recommendations submitted by the HRSA AIDS Advisory Committee to meet the challenges ahead. The CARE Act plays a vital role in filling gaps, such as variability in coverage between States. By limiting access to primary care and pharmaceuticals, different Medicaid eligibility levels directly affect health outcomes. An important element in reducing disparities is supporting integration of systems of care between Medicaid, CARE Act and other publicly-funded programs. Including and promoting quality assurance and performance improvement is also essential in monitoring program effectiveness and creating delivery systems that meet the needs of the most vulnerable populations affected by HIV. Still another key element in ensuring quality care is training providers on appropriate standards of care and improving practice and service delivery.

The legislation should ensure that those funds set aside for evaluation and administrative activities related to the CARE Act are made available primarily for that purpose within the AIDS programs of the administering agency.

SPNS—The current \$25 million on spending for the Special Projects of National Significance (SPNS) Program should be increased with additional resources made available for replication of successful care and service models developed through the CARE Act. Funding for the increase might be made available by removing the \$25 million cap on SPNS and then by using funds from the 3 percent set-aside already authorized.

24. Evaluation

The legislation should reinforce current HRSA evaluation activities by directing HRSA to establish standardized evaluation measures and instruments that will allow for assessment of patient outcome, care processes, and client satisfaction experiences.

25. Quality Improvement

Grantees providing clinical care should demonstrate the existence of quality improvement initiatives and linkages to appropriate local HIV training centers to ensure that appropriate clinical standards are implemented.

For non-clinical services, such as transportation and food services that are provided under Titles I and II, grantees should demonstrate efforts to assess the efficacy of services and document steps taken to meet appropriate standards, including an improvement plan, when deficiencies are noted.

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* Dr. Aranda-Naranjo will join the HIV/AIDS Bureau in October 1999 and will no longer be a member of the HAAC.

HRSA CareACTION

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HRSA CareACTION

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

HRSA AIDS Advisory Committee
Makes Recommendations for
CARE Act Reauthorization

An important responsibility of the Health Resources and Services Administration (HRSA) AIDS Advisory Committee (HAAC) is to submit recommendations to HRSA and the Secretary of Health and Human Services regarding reauthorization of the Ryan White CARE Act, currently being considered by the Congress.

To meet this objective, the HAAC undertook a comprehensive review of issues, needs, and trends related to the epidemic. The review process included:

- Two public hearings, one in San Antonio on October 9, 1998 and another in Washington, DC on December 3-4, 1999;
- Solicitation and review of input from CARE Act grantees, community groups, consumers and providers, and review of written testimony;
- Discussion of draft recommendations at a public meeting on May 13-14, 1999; and
- Final consideration and refinement of recommendations in August 1999.

The review process concluded with the submission of this report to the HRSA Administrator and the Secretary of Health and Human Services in September 1999.

Legislative Recommendations
as Written and Adopted by the HAAC

1. Reauthorization of the Ryan White CARE Act

The Ryan White CARE Act should be reauthorized.

2. Structure of the CARE Act

A reauthorized CARE Act should retain the basic existing title structure, including:

- Title I: Emergency Relief for Areas with Substantial Need for Services;
- Title II: HIV Care Grants to States;
- Title III: Early Intervention Services;
- Title IV: Grants for Coordinated Services and Access to Research for Women, Infants, Children and Youth; and
- Part F: Special Projects of National Significance; AIDS Education and Training Centers Program; HIV/AIDS Dental Reimbursement Program.

3. Formula Issues: Titles I and II

The legislation should instruct the Secretary of Health and Human Services to consult with appropriate experts and/or to commission a study to explore the implications of various options for developing a new formula method for distribution of CARE Act funds in the future. Such an undertaking should be completed within 1 year after reauthorized funds are appropriated and should look at potential use of HIV case data, care provision data, cost data, and other possible methods for distributing funding to meet HIV care needs across the country.

Continued on Page 2

4. *Hold Harmless Provisions of Formula — Titles I and II*

Under a reauthorized CARE Act, the existing provisions of the law that limit the loss of resources to a jurisdiction over time should be retained, ensuring that no jurisdiction will receive less than 90 percent of their fiscal year 1995 award in the 2005 fiscal year.

5. *Funding Distribution — Title II*

A competitive funding program should be developed within Title II to respond to severe unmet need in States or portions of States. This should be accomplished by setting aside a portion of the national Title II appropriation and making it available for competitive application to States for the development and care delivery activities outside of Title I EMAs. Legislative authority should be given to HRSA to award these competitive funds based on unmet need and the ability of the applicant to fill gaps in essential services using these funds. (Existing hold harmless language should be retained to ensure that this funding comes from new dollars rather than shifting needed services from other States.)

6. *Title II — ADAP Formula Distribution*

While the distribution of ADAP funds in Title II should continue to be based on a case driven formula, a small percentage (up to 10 percent)

of the ADAP appropriation should be made available for award by HRSA based on a competitive application.

Priority in awarding these funds should go first to assisting jurisdictions in providing the full range of treatments necessary to meet the Public Health Service (PHS) treatment guidelines for low-income persons with HIV, and then to jurisdictions that will be able to cover additional low-income individuals. Part of the competition may be used to provide incentive to jurisdictions to make State/ local funding available for this purpose or to enhance their State Medicaid eligibility guidelines.

The HRSA AIDS Advisory Committee (HAAC) was established in 1988 to advise HRSA and the Department of Health and Human Services on program and policy issues related to the HIV/AIDS epidemic in the United States. Members have expertise in fields related to HIV/AIDS service delivery as well as a working knowledge of the Ryan White CARE Act and HRSA AIDS programs. HAAC members include health care providers, advocates, and people living with HIV disease. The HAAC helps ensure quality care for people living with HIV by providing counsel regarding program implementation and emerging needs and trends, and by making recommendations for legislative and administrative policy.

7. *Statewide Coordinated Statement of Need*

In addition to those partners specified in the existing legislation (individuals with HIV, representatives of grantees under each Title, providers, and public agency representatives), the legislative requirement for a periodic meeting to develop a Statewide Coordinated Statement of Need should also specify the desirability of participation of other publicly-funded agencies serving vulnerable populations. These should include:

- Maternal and Child Health Bureau, HRSA
- Health Care for the Homeless
- Medicaid
- Medicare
- Mental health and substance abuse services
- Indian Health Service
- Housing Opportunities for People with AIDS
- Centers for Disease Control and Prevention (CDC) counseling and testing, prevention, and outreach program representatives
- Representatives from corrections and probation
- Youth serving agencies
- Other similar relevant providers

8. *Title I HIV Health Services Planning Councils — Composition*

The legislative language concerning composition of the planning councils should be strengthened to require that the composition of the planning council reflect the current status of racial/ ethnic and risk factor demographics of the local epi-

demic, and that consumer representation reflect the same characteristics. Demonstration of this should be a requirement of funding under this section of the Act. Additionally, language should be added specifically to ensure representation of women, youth, substance abusers, gay men, adolescents, and people of color living with HIV.

The legislation should mandate that a minimum of 33 percent of the members of planning councils be people living with HIV.

The legislation should require that planning councils provide training to support consumer participation and allow expenditures to support consumers' training and participation.

A primary concern for HAAC members in submitting recommendations for reauthorization is addressing the disparity in access to care and quality of care. While barriers to care have been reduced for some underserved populations, significant variations remain based on race, ethnicity, gender, and type of coverage. Beyond ensuring access to care, CARE Act programs must also ensure that people with HIV receive quality services and care. This means elevating the quality of care throughout health delivery systems at all levels from point of service to establishing and maintaining infrastructure.

Continued on Page 4

Trends in the Epidemic Influencing HAAC Recommendations

- Since HIV incidence (annual infections) is greater than AIDS mortality (annual deaths), the total number of individuals living with HIV disease in America is on the increase.
- An estimated 650,000 to 900,000 persons are living with HIV disease today. More than 270,000 persons have progressed to AIDS.
- The decline in new HIV infections has stopped. HIV incidence is estimated at about 40,000.
- Up to one-third of all HIV-positive individuals do not know they are infected. Tens, perhaps hundreds of thousands additional individuals know they are HIV positive but are not receiving care regularly.

- Highly active antiretroviral therapy (HAART), introduced in 1996, has prolonged and enhanced quality of life for persons living with HIV/AIDS. However, the majority of individuals living with HIV disease are not receiving HAART, and benefit from the therapy is unequal among those currently utilizing it.
- The number of annual AIDS deaths (AIDS mortality) dropped 42 percent between 1996 and 1997. Between 1997 and 1998, however, deaths dropped by only 20 percent.

Since the beginning of the epidemic, more than 688,000 people have been reported with AIDS and 410,800 have died.

New AIDS Cases Reported in 1998 by Race and Ethnicity

Race/Ethnicity	No. of New AIDS Cases	Percent of New AIDS Cases	Percent of Population
White, non Hispanic	16,116	34%	73%
Black, non Hispanic	21,752	45%	12%
Hispanic	9,650	20%	11%
Asian/Pacific Islander	390	< 1%	4%
American Indian/Alaskan Native	147	< 1%	< 1%
Total	48,055	100%	100%

Continued on Page 4

including payment for necessary expenses such as child care, transportation, hotels and meals, as well as reasonable stipends for time participating in planning activities. A majority (at least 51 percent) of planning council members must be free of conflict, as defined by the current legislation.

9. Title II — Participatory Planning

Within Title II of a reauthorized CARE Act, we recommend that a legislative mandate be created for an open advisory planning process that includes people living with HIV and a range of representatives from affected communities and service providers.

States receiving Title II funds should be required to demonstrate that such a participatory process exists and is consulted in decisions about needs assessment and priority setting for Title II funds and that consumer participants are provided training to support their participation.

Consortia funded through Title II of the CARE Act should be required to demonstrate that their membership includes representation reflecting the epidemiology of HIV/AIDS in their geographic area and includes people living with HIV/AIDS as well as providers of services to impacted populations. Consortia should be required to conduct open nomination processes and to conduct open business meetings.

10. PHS Guidelines as Priority for CARE Act Services

Implementation of PHS guidelines for HIV treatment and care should be a priority for grantees. As a condition of award, all CARE Act grantees should be required to document the extent to which people living with HIV in their area of service are receiving care that meets or exceeds PHS guidelines and that specific steps are being taken to improve treatment and care.

11. Priority to Core Services and Linkages to Health Care

A reauthorized CARE Act should instruct grantees to prioritize and allocate resources, as appropriate to: the service needs of their locality; provision of primary care and therapeutics; and those activities necessary to assist consumers in gaining and maintaining access to medical care and therapeutic agents, including consumer treatment education.

It is recognized that social service activities supported by the CARE Act should actively assess the involvement, access, and barriers to care of clients. Such social services should seek to voluntarily connect into health care those not currently accessing it, while respecting client choice and autonomy around care decisions.

A reauthorized CARE Act should continue to recognize that, in many instances, a variety of supportive services may be necessary to connect and maintain people in health care. Provision and/or coordination of those essential services

12. Early Intervention Certification Requirement—All Titles

As a condition of award, Title I, Title II, Title III and Title IV grantees should be required to certify and demonstrate linkages with the appropriate HIV detection, early intervention services, prevention, surveillance, and substance abuse treatment resources in their jurisdictions. Specifically, this should include documentation of ties to local counseling/testing programs and, for government grantees, cooperation and planning with those agencies responsible for counseling/testing that may be demonstrated by memoranda of understanding.

13. Serving Vulnerable Populations — Titles I and II

Grantee responsibility for Title I and Title II in the legislation should explicitly include a requirement to assess the needs of vulnerable populations not currently in care and to develop a plan to meet those needs.

As a condition of award, grantees must be able to demonstrate that they have meaningful linkages (such as contracts, memoranda of understanding, co-located staff, etc.) with service providers likely to be the point of entry into care for vulnerable populations not currently accessing HIV care (such as: emergency rooms, sexually transmitted disease clinics, migrant health centers, family planning clinics, homelessness service providers, street youth programs, substance abuse treatment programs, etc.). The scope and nature of such linkages shall

depend on the services provided and populations served by the grantee.

14. Meeting the Care Needs of HIV-positive Women

In setting service priorities for primary care, all CARE Act-funded grantees should recognize the importance of obstetrical and gynecological services for HIV-infected women and address access to those services as part of their access plan.

Title I program resource allocation should reflect the percentage of women in the local epidemic, and these funds should not be solely linked to perinatal services or focused solely on mothers.

15. Title IV — Elimination of Research Requirement

The reauthorized CARE Act should be changed to state that "women, infants, children and youth who are patients of the applicant will be offered the opportunity to participate in projects of research and either accept or knowingly reject that opportunity" (from the existing language that "requires" participation).

16. Dental/Oral Health Care

In a reauthorized CARE Act, the present program of supporting dental school clinics for care of oral health needs of people with HIV should be retained. Alternative methods of awarding these funds, including requiring competitive proposals, should be considered.

Continued on Page 6

Minorities

- The proportion of new AIDS cases among people of color, adolescents and young adults, heterosexuals, and people living in the South has continued to increase in recent years.
- Non-Hispanic Blacks and Hispanics accounted for 45 percent and 20 percent, respectively, of reported AIDS cases in 1998, up from 30 percent and 17 percent, respectively, in 1990.

Men who have sex with men

- Young gay and bisexual men, particularly Black gay and bisexual men, show increasing high risk behav-

ior. Recent studies of young gay and bisexual men show that Black gay and bisexual males were nearly two to five times as likely to be infected with HIV as their White counterparts.

Women

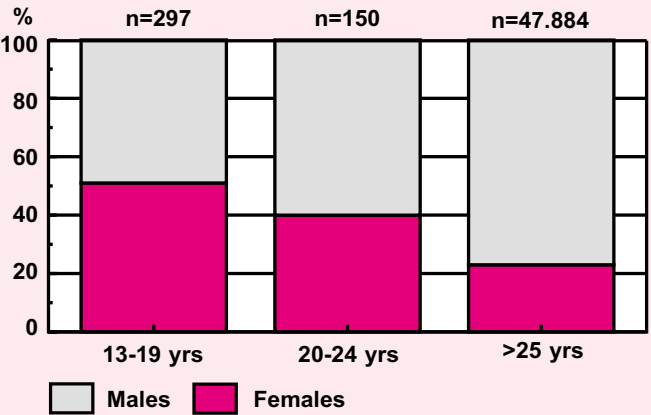
- The proportion of new AIDS cases among women continues to rise. In 1998, women represented nearly one out of four (23 percent) new cases of AIDS, up from 11 percent in 1990.
- Women of all ages are most likely to be infected through heterosexual contact, most often with an injection drug user.

- The majority of women with HIV and AIDS are women of color: 62 percent of new female AIDS cases in 1998 were among African Americans and 19 percent among Hispanics.

Youth

- As many as one-half of new HIV infections occur in youth under age 25; one in four are in young people under age 22.
- A disproportionate number of reported AIDS cases among adolescents are among ethnic and racial minorities. At highest risk are African American youth, who comprised 58 percent of reported cases during 1998 in the 15 to 24-year-old age group.

New Cases of AIDS -- 1998



Continued on Page 6

In addition, funds should be made available on a competitive basis to support community-based clinics providing dental care for people with HIV, especially in communities without a participating dental school clinic or with high unmet oral health care needs. Such a competitive program should be administered in a manner similar to the existing Title III of the CARE Act.

Oral health should remain an allowable service category under other Titles of the CARE Act.

17. AIDS Education and Training Centers

The existing mandate for AIDS education and training centers should be altered in a reauthorized CARE Act. Specifically, it should no longer be a focus of AETCs "to train the faculty of schools, graduate departments and programs of medicine, nursing, osteopathic medicine, dentistry, public health, allied health and mental health practice to teach health professions students to provide for the health care needs of individuals with HIV disease."

Instead, this mandate should be replaced with a focus on providing training relevant and appropriate to the needs of providers and HIV-positive consumers of health services in the region in which the AETC operates, with particular priority given to training providers who will deliver services to CARE Act clients, and to expanding the number of minority providers who provide care to people with HIV/AIDS.

18. ADAP — Funding Flexibility

The legislation should allow ADAP funds to be

redirected by the State grantee to other essential services under some limited circumstances. The current availability for ADAP funds to be used to purchase insurance when economically advantageous should be retained.

In addition, when an ADAP is already able to provide full coverage of the drugs necessary to meet the PHS treatment guidelines for all low-income people living with HIV in their State, they should be able to apply for and receive permission from HRSA to apply ADAP funds to other essential HIV/AIDS care activities in their State, including services that assist people in accessing and maintaining treatment services.

19. Flexibility to Support Integration of Federally-funded Programs

A reauthorized CARE Act should include the option of allowing grantees to apply to the Department of Health and Human Services (DHHS) for authority to combine parts of funding currently received under different Titles of the CARE Act with other Federal resources (HIV counseling/testing, substance abuse treatment, outreach and prevention, STD detection and treatment) in order to enhance early detection and intervention. This flexibility may be as simple as allowing jurisdictions to adjust internal contracting processes and timetables in order to issue jointly-funded requests for proposals.

20. Demonstration Project Authority—Combining Multiple Funding Streams

The reauthorized CARE Act should provide

seeking to combine various Federal funding streams supporting HIV/AIDS care and services. Such a waiver would allow a State to combine Federal and State Medicaid, Medicare, CARE Act and, potentially, parts of funding from the Substance Abuse and Mental Health Services Administration (SAMHSA) and CDC. Such waiver authority would require submission of an application documenting how such a demonstration project would allow the jurisdiction to provide access and quality care to more individuals with HIV/AIDS. In addition to direct funding for health care, the demonstration project would be required to include access to supportive services enabling a person to enter and remain in care.

21. Administrative Cost Issues — All Titles

We recommend that a reauthorized CARE Act specify that:

- *Quality improvement activities are a legitimate programmatic cost that should not be counted against the administrative spending limits;*
- *Evaluation activities are essential to quality programs and grantees should be allowed to devote up to 5 percent of their total grant to evaluation activities; and*
- *HRSA be granted the authority to make exemptions to the uniform 10 percent overhead/administrative rate limit for Title I and II grantees and sub-grantees to provide up to 20 percent in cases where the grantee or sub-grantee is a small community-based organization without well developed infrastructure and such an exemption enables the*

capacity of that organization to provide CARE Act services.

22. All Titles — Grievance Procedures

The legislation should require that all grantees funded under the CARE Act establish appropriate procedures allowing consumers of CARE Act-funded services to pursue grievances against providers. HRSA should be instructed to establish guidelines for these locally run procedures, including standards for informing consumers of grievance rights, encouragement of mediation, rights of all affected parties, and access to appeal mechanisms external from the grantee.

23. Re-evaluation of Current Set-aside Provisions

A reauthorized CARE Act should alter the way in which set-aside funds are distributed.

The 1 percent of CARE Act funds that currently go to DHHS should go directly to HRSA.

The set-aside funds should:

- *Continue to be available for technical assistance activities, with new emphasis on providing those activities in underserved and heavily impacted communities;*
- *Be made available to support national and regional efforts to educate consumers about treatment options and access to care; and*
- *Be made available for HRSA to make grants to solicit competitive bids to address pressing needs for infrastructure and capacity development.*

Continued on Page 8

Substance abuse

- Substance abuse is a factor in well over 50 percent of HIV infections in some cities.
- In 1998, injection drug use was the exposure category in 21 percent of AIDS cases in men and 29 percent of cases in women, and people of color continue to be disproportionately affected.
- Heterosexual transmission through sex with an IDU was the exposure category in at least 4 percent of cases.

Care issues

According to the 1996 *HIV Cost and Services Utilization Study*—the largest and most representative study ever completed of HIV positive individuals in care:

- Only 335,000 of the estimated 650,000 to 900,000 HIV-positive individuals in America were being seen at least once every 6 months (far below the standard of care) in 1996;
- Substantial gains have been made during the past several years for HIV-positive individuals who are receiving care. Seven out of ten people in care in 1996 failed to receive at least one of six indicators

used to assess quality of care, including receipt of antiretroviral therapy and making at least two outpatient visits. By early 1998, however, nearly one-half (47 percent) obtained all six indicators for which they were eligible. Latinos no longer lagged behind Whites in five of the six measures, while the disparity between African Americans and Whites dropped from 24 percent to 8 percent. The gap between uninsured persons and Medicaid recipients fell by one-half between African Americans and Whites dropped from 24 percent to 8 percent. The gap between uninsured persons and Medicaid recipients fell by one-half.

- The study found that the vast majority of people who receive care are seen by providers with experience in caring for people with HIV disease, and who are likely to adopt new treatment regimens early on.
- The gap between care for women and men was essentially unchanged from 1996 to 1998. And African Americans, Medicaid-funded, and uninsured persons continue to receive poorer quality care than others with HIV disease, despite improvements.